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**INTERDEM Academy Special Section - Digging for Dementia: Exploring the experience of community gardening from the perspectives of people with dementia**

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# **INTERDEM Academy Special Section - Digging for Dementia: Exploring the experience of community gardening from the perspectives of people with dementia**

## **Abstract**

### ***Objectives***

The study sought to explore the lived experiences of people with dementia who participate in community-based gardening programmes.

### ***Methods***

A collaborative gardening project was conducted over six weeks at a day centre for people with dementia. Six participants were recruited from the centre's attendees. Each session was co-designed by participants. Semi-structured group interviews were conducted each week, and researcher observations were documented. Semi-structured interviews were also conducted with the centre's staff to explore their views and to contextualise gardening participants' experiences. Data were analysed inductively using thematic analysis. This paper focuses upon three of the study's emergent themes: identity, agency, and community.

### ***Results***

The findings revealed that for people with dementia, gardening is not merely a matter of enjoying time outdoors; it is a forum for the articulation of identity and selfhood and expression of agency, and can facilitate the development of new social bonds based upon shared interests, rather than a shared diagnosis.

### ***Conclusion***

Gardening-based interventions can offer more than simply facilitating outdoor engagement and promoting social interaction. When conditions are right, gardening can be an effective vehicle for the promotion of social citizenship and expression of selfhood and agency in dementia.

Keywords: dementia, gardening, citizenship, selfhood, community

## Introduction

### *Living with dementia*

There are currently 9.25 million people living with dementia in Europe (Alzheimer Europe, 2013). Consequently, dementia is considered a public health priority throughout the European Union, with the European Parliament highlighting the importance of promoting well-being for people with dementia to improve the lived experience of the condition (European Parliament, 2011). In the UK, support for people living with dementia in the community is often lacking, with limited opportunities to participate in meaningful activities such as gardening (Knapp et al, 2007), leading many people living with dementia to express feelings of depression, loneliness, and isolation (Lakey et al, 2012).

Though the discourse surrounding dementia has evolved to encourage a more positive perception of the condition, living with dementia remains an often challenging experience, potentially disempowering individuals, fuelling a loss of social identity, and introducing the stigma associated with the condition, which many people with dementia internalise, contributing to feelings of shame and lack of self-worth (Swaffer, 2014). Dementia has historically been characterised by a gradual erosion of self (Davis, 2004); however, research increasingly suggests that a sense of self persists throughout the dementia journey (Caddell and Clare, 2010), with Kontos (2004) positing that the presumed loss of self in dementia is a consequence of the Cartesian mind/body dualism that drives Western conceptualisations of selfhood, positioning cognition as essential to selfhood, and the impairment of memory as therefore indicative of loss of self. Kontos (2011) proposes a theory of embodied selfhood to encourage acknowledgement of the role of the body in expressions of selfhood for people with dementia.

Agency- an individual's capacity to initiate social action, make free choices, and influence their personal circumstances (Boyle, 2014)- remains lacking in the lives of many people with dementia, with those living with the condition presumed to possess little to no agency. However, Boyle (2014) asserts that this presumed lack of agency is a consequence of limitations in agency theory, which focuses upon rationality, intentional action, and language as expressions of agency, thereby excluding groups such as people with dementia, who may be unable to exercise agency within such boundaries.

Rather than assuming a lack of capacity on the part of people with dementia, researchers and care practitioners must re-examine the parameters within which concepts such as agency and selfhood are currently understood in the context of dementia, to truly obtain insights into the lived experiences of people with dementia, and the ways in which people with dementia interact with their physical and social environments.

### ***Gardening and dementia***

Facilitating interaction with nature can promote well-being (Wolsko & Lindberg, 2013), reduce anxiety (Martyn & Brymer, 2016), and encourage social interaction (Clatworthy et al, 2013), potentially addressing some of the challenges affecting people with dementia (Noone et al, 2015). Despite increasing acknowledgement of the importance of access to nature, a significant proportion of people with dementia are deprived of regular contact with the outdoors; 50% of care home residents with dementia never go outside, with a further 25% going outdoors only rarely (Gilliard & Marshall, 2012). Community-dwelling people with dementia are prevented from accessing natural environments by a variety of factors, including transportation and physical access to outdoor spaces, lack of self-confidence, and fear of stigma (Mapes et al, 2016).

Leisure activities such as gardening offer an opportunity for people with dementia to experience a sense of freedom, challenging the power structures that inform their daily lives (Genoe, 2010). Such activities can enable people living with dementia to live beyond the stigma and stereotypes associated with their condition; as Wearing (1998, p. 146) articulates, environments such as a community garden can provide “*a space where there is room for the self to expand beyond to what it is told it should be.*” Community gardens have been identified as a forum for social change and activism; the garden has become a place of inclusion, identity, and expression (McKay, 2011), offering a safe space in which individuals and groups can feel liberated from the social structures that perpetuate the inequalities they experience (White, 2011).

A small number of studies have investigated the impact of gardening upon people with dementia, demonstrating improvements in well-being through cultivating a sense of enjoyment and purpose, (Hewitt et al, 2013); increased displays of active and passive engagement (Jarrott & Gigliotti, 2010); and enhanced levels of cognitive functioning (D’Andrea et al, 2007). However, only one study (Hewitt et al, 2013) explored the potential of gardening for people

with dementia in a community setting, with the majority of research focusing upon care home settings, indicating a significant gap in the knowledge base concerning gardening for community-dwelling people with dementia. Additionally, by focusing upon specific outcomes, the existing research does not offer a holistic understanding of the factors influencing the meaning of gardening for people with dementia. Furthermore, the outcomes of these studies were assessed using researcher observations or carer-assessed outcome measures, rather than participant feedback, and may therefore not reflect the lived experiences of people with dementia.

### **Aims and objectives**

The study sought to explore how people with dementia experience participating in community-based gardening initiatives.

To achieve this aim, the following objectives were established:

- To deliver a community-based gardening programme for people living with dementia
- To explore the participants' experiences of the gardening sessions, using a variety of qualitative and inclusive data collection techniques
- To explore the experience of the gardening programme from the perspectives of those who care for the participants with dementia, using qualitative semi-structured interviews

### **Research Design**

The study consisted of weekly gardening sessions for people with dementia, to explore the subjective experience of gardening from participants' perspectives. Data concerning participants' lived experiences were collected via qualitative interviews, and complemented by the researcher's observations and interviews with the day centre staff. Qualitative interviews were conducted with three professionals who had experienced working with people with dementia in the garden, to establish the generalisability of the findings.

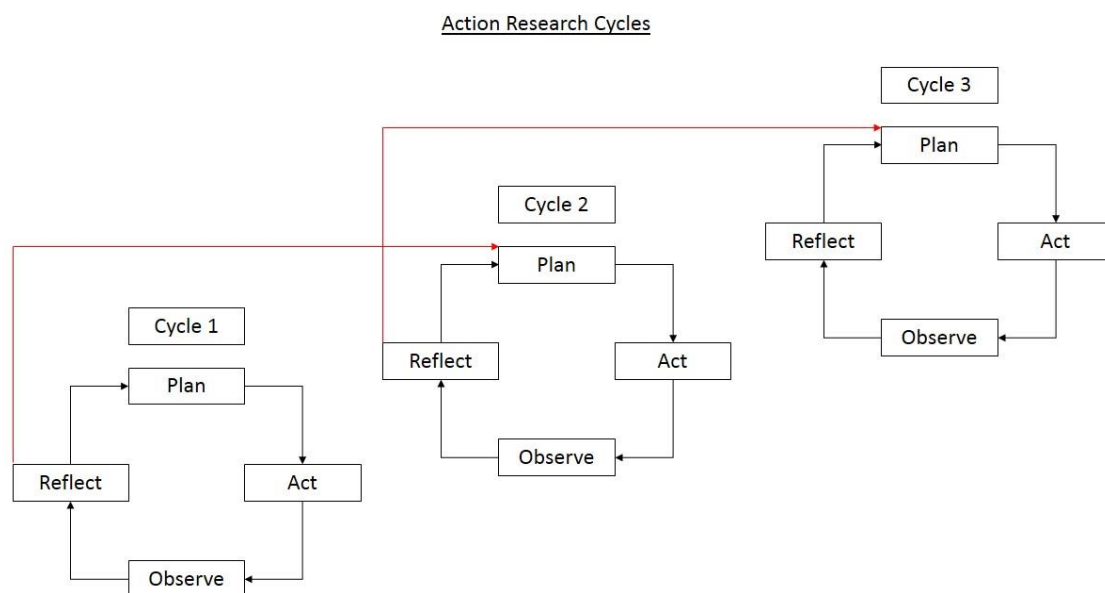
## Methodology

The study was guided by a pragmatist methodological perspective, drawing upon elements of phenomenology and action research.

The design of the gardening project was informed by an action research approach, drawing upon Kurt Lewin's (1946) philosophy of research as a symbiotic relationship between the development of practical improvement and the pursuit of theoretical knowledge, which is in turn informed by a democratic relationship between researcher and participants.

Lewin (1946) conceptualised action research as a cyclical process in which a potential solution to a problem is formulated and delivered, its success evaluated, and the feedback from the proposed solution reflected upon to further inform its development (see Fig. 1). This cyclical process was fundamental to the design of the gardening programme, as each session formed an action research cycle. The feedback obtained from participants at the end of each session informed the planning of the subsequent session, driving the project further towards the 'optimal solution' to the research problem.

Figure 1: Action research cycles



The data collection methods applied during the study were guided by phenomenological principles, to facilitate understanding of the meaning of community gardening from the perspectives of people with dementia. The small sample size and qualitative, inductive data collection tools associated with phenomenological studies enabled the researcher to form relationships with the participants and immerse themselves in the data, contributing to a deeper interpretation of the group's experiences of the activity.

Furthermore, interpreting the meaning of an individual's lived experience through a phenomenological lens facilitates an understanding of the myriad ways in which such meaning may be communicated. A phenomenological definition of 'lived experience' incorporates four elements- lived space, lived body, lived time, and lived human relations (Van Manen, 2016). This broadened definition of the 'lived experience' is particularly pertinent when working with people with dementia, who, as previously explored, may face challenges when seeking to express themselves within the pre-defined parameters imposed by wider society. By applying a less restrictive definition of the construction of meaning, phenomenology offers a more holistic and inclusive approach to interpreting the meaning of a particular phenomenon- in this instance, a community garden- for people living with dementia.

### ***The garden***

The garden was located in the grounds of a community hall in Glasgow, Scotland, UK, which hosted a day centre for people with dementia. Following an initial email introduction, the researcher met with the manager of the day centre to introduce the study and discuss the role of the centre in the research.

### ***The participants***

A summary of participants is provided in Table 1. Six day centre attendees participated in the study. The participants self-selected following an introductory discussion with the centre's manager, and a subsequent group meeting with the researcher to discuss the research and their role in the process.

Minimal exclusion criteria were applied during the recruitment process, to reflect the pragmatist view that the participants selected for a study should resemble those who would



take part in the activity in question in a real-life setting (Glasgow, 2013). Therefore, three inclusion criteria were applied: participants must have a diagnosis of dementia, must be able to provide informed consent to participate in the study, and must be willing and able to undertake the light physical activity associated with gardening. Participants with a diagnosis of any type of dementia, as confirmed by the day centre's manager, were considered eligible to participate in the study.

Initial ethical approval for the study was obtained from the University of the West of Scotland School of Health, Nursing & Midwifery ethics committee (application reference SEC/SHNM/APRL16/055), with subsequent amendments approved by the University's School of Media, Culture & Society's ethics committee (application reference MCS-2016-Noone-30-08-26).

### ***Consent***

During the preliminary meeting, the potential participants were provided with a copy of the information sheet and consent form and offered the opportunity to ask questions. They were invited to consult the information sheet with their families, and contact the researcher with any questions, before returning their consent form at the first gardening session. The participants' ability to provide informed consent was established through initial discussion with the centre's manager, and through discussion and observation during the preliminary meeting.

During the sessions, the researcher employed a process consent approach (Dewing, 2007) to monitor the participants' engagement and assess their willingness to participate in activities. The researcher established a basis for consent during the preliminary meeting, observing the participants to understand how each individual communicated their state of well- or ill-being. Over the course of the gardening project, the researcher developed a relationship with each participant, facilitating the development of an understanding of the participants' verbal and non-verbal cues, and creating a mutual trust with the participants that enabled them to feel comfortable communicating their level of willingness to participate in a particular activity.

Following completion of the gardening initiative, the researcher conducted semi-structured interviews with the centre's staff. The researcher approached the staff with the centre manager's authorisation to establish their willingness to participate and after obtaining verbal consent, the researcher distributed the written consent form and information sheet via email.

The staff were invited to ask any questions prior to participating, before returning the signed consent form prior to commencement of the interview. The interviews were conducted at the day centre before the members arrived, to minimise disruption to the staff members' routines.

Semi-structured interviews were conducted with two community gardeners, and one occupational therapist, who had experienced working with people with dementia in the garden. Participants were recruited following initial email contact via professional networks. Information sheets and consent forms were distributed via email, and the participants were invited to ask questions prior to commencement of the interview. The interviews were conducted at locations suggested by the participants.

Table 1: The participants

<b>The gardeners</b>	
<b>Arthur</b>	Arthur is a lifelong gardener, who has always taken great pride in his home garden. The staff of the day centre expressed their admiration for Arthur's garden to the researcher on a number of occasions. However, as Arthur's dementia journey continued, he had become less able to spend time in his garden, and his gardening activity now consists solely of tending his roses, which he greatly enjoys.
<b>Sheila</b>	Sheila has been gardening since childhood, and often shared her memories of gardening as a child with the group. Sheila possesses an extensive knowledge of gardening, and generously shared her skills and expertise with the group during the sessions. She was a humorous, friendly member of the group, who enjoyed sharing her skills with her fellow participants and undertaking a supervisory role during the gardening activities.
<b>Ethel</b>	Though Ethel enjoys the outdoors, she had limited experience of gardening before joining the study. Ethel lives in an upper cottage flat, with no access to a garden at home. Ethel was an enthusiastic, positive member of the group, who always complimented the researcher's work and shared how much she had enjoyed the sessions.
<b>Victoria</b>	Victoria enjoys her garden, and spoke enthusiastically about her daughter's gardening skills, but has limited opportunities to garden at home. Victoria was the natural leader of the group; proactive and enthusiastic during sessions, forthcoming with suggestions for activities, and nurturing and supportive towards her fellow participants.
<b>Claire</b>	Claire does not have a garden at home, but has fond memories of working in the garden as a child, and enjoys outdoor activities such as walking in the park. The day centre's staff advised that Claire's personal journey with dementia had progressed further than those of her fellow participants, and she sometimes found herself unable to follow instructions during the practical tasks; however, she continued to participate by helping the researcher to oversee the activities, and supporting her fellow participants.
<b>Bridget</b>	Despite being the quietest member of the group, in part due to her hearing difficulties, Bridget was a keen participant in the gardening sessions, and enjoyed the social element of the project. Bridget was not a gardener prior to participating in the study; however, she eagerly participated in the gardening activities, particularly enjoying the core tasks such as seed planting and re-potting.
<b>The care workers</b>	
<b>Joanne</b>	Joanne is a care worker at the day centre, and acts as key worker to Arthur, Ethel, and Bridget
<b>Judy</b>	Judy is the manager of the day centre, and supports all of the study's participants
<b>Maggie</b>	Maggie is a care assistant at the day centre, and provides support to all of the study's participants
<b>Rebecca</b>	Rebecca is a care worker at the day centre, and acts as key worker to Claire, Victoria, and Sheila
<b>The professionals</b>	
<b>Lauren</b>	Lauren is an occupational therapist, who recently worked closely with a person with dementia in her home garden as a form of rehabilitation
<b>Megan</b>	Megan oversees a community allotment project for people living with dementia
<b>Jennifer</b>	Jennifer developed a community garden designed for people with Alzheimer's disease

### ***The sessions***

Gardening sessions were conducted weekly over a six-week period. A summary of gardening activities is provided in Table 2. Most of the day centre attendees who expressed interest in participating attended the day centre only on Mondays, and sessions were therefore held each Monday, to minimise disruption to the participants' routines. Following each session, participants were invited to suggest activities which were incorporated into the subsequent session, further encouraging the collaborative nature of the project. Every activity conducted during the project was selected by the participants, indicating that the group responded positively to this participatory approach to designing the sessions.

Table 2: Summary of weekly sessions

Week	Summary of activities
1	As the participants were unable to choose the session activities beforehand, the researcher arrived at the first session with a variety of vegetable and flower seeds, and options for craft activities, and invited the participants to decide how they would like to spend the session. The pre-session meeting held between the researcher and participants the previous week had offered the researcher some insight into the group's preferred activities; however, the researcher wished to ensure that the participants were able to choose the initial gardening activities, rather than making assumptions regarding their preferences. The group opted to plant carrot and broccoli seeds in the raised beds, and to make coconut bird feeders to be displayed in the garden.
2	During the week one post-session interview, Arthur suggested that the group plant salad vegetables, and Sheila expressed that they would like to plant cut-and-come-again vegetables. The researcher led the group in planting spring onions and lettuces, combining these suggestions. Victoria and Sheila expressed a particular interest in hanging baskets. During the latter half of the session, the researcher led the group in planting hanging baskets, using a variety of bulbs and wildflower seeds.
3	During prior interviews, Victoria had expressed a keen interest in planting runner beans, and the session began with the group planting the beans in small troughs. Several of the participants had shared that they would enjoy planting fruit trees, and the session concluded with the planting of an apple tree sapling, which was planted alongside the garden's existing fruit trees.
4	This session was conducted indoors due to inclement weather. The session began with the group thinning out the runner bean seedlings, which had sprouted very successfully in the week between sessions. Following the third session, Ethel asked whether the group could grow tomatoes, and Victoria added that she would like to grow cucumbers. To maximise the possibility of germination so late in the growing season, the researcher propagated several tomato and cucumber seeds at home, and the group were therefore able to plant small cucumber and tomato seedlings. Once planted, the seedlings were placed in the polytunnel. The session concluded with the planting of nasturtiums, as suggested by Sheila during the previous week's discussion. The nasturtiums provided an opportunity for the group to learn about companion planting, as nasturtiums are often planted alongside vegetables to deter pests.
5	The group began by thinning the cucumber, tomato, and runner bean seedlings, which had progressed significantly between sessions. During the fourth post-session interview, Sheila, Arthur, Claire, and Ethel expressed that they would like to plant vegetables that would grow over the winter. The researcher opted to dedicate the fifth session to leafy vegetables that could be grown over the winter, and led the group in planting spinach, pak choi, and chard. The group selected these seeds from a wider selection of winter leafy vegetables, ensuring that the participants retained a sense of control over the crops planted. The first half of this session was conducted in the polytunnel due to rain, and the group expressed that this was an enjoyable and educational experience.
6	The final session began by thinning the seedlings planted during the previous three sessions, which had continued to sprout successfully in the polytunnel. Continuing to implement the participants' suggestion to plant vegetables that could be maintained over the winter, the researcher led the group in planting winter root vegetables: parsnips, beetroot, and turnips. Once again, the group decided which vegetables they would like to plant by choosing from a wider selection of root vegetable seeds, ensuring that the activities selected remained driven by the group's preferences.

### ***Data collection***

A mixed methods approach was used to explore the participants' experiences of the study. Though researcher observations were also collected, the researcher sought to prioritise capturing first-person perspectives from participants. Informal, semi-structured group interviews were conducted with participants following each session, to facilitate discussion, explore the participants' views concerning the week's activities, and provide an opportunity to suggest potential improvements to the sessions.

The researcher prepared questions before each interview, guided in part by the day's activities and previous discussions. However, to encourage the discussion to flow naturally, the researcher intervened as little as possible. The interviews were audio-recorded and transcribed. Though the information sheet stated that the interviews would be recorded, the researcher obtained verbal consent from participants before each interview.

The researcher documented their observations following each session. These observations performed a dual purpose: to provide a narrative of the session, and to record the researcher's reflections. The researcher also documented any issues highlighted during the session, and reflected upon potential improvements.

Individual semi-structured interviews were conducted with the centre's staff following completion of the gardening project. Though the researcher prepared a small number of questions, the overall discussion flowed freely to encourage the interviewees to share their thoughts in an organic manner. The interviews were audio-recorded, and transcribed.

Individual semi-structured interviews were conducted with three professionals- one occupational therapist, and two community gardeners- who had experienced working with people with dementia in the garden. These interviews were intended to establish the generalisability of the study's findings by discussing the emerging themes in relation to the interviewees' experiences. The interviews were audio-recorded, and later transcribed.

### ***Data analysis***

The interview transcripts and researcher observations were analysed using thematic analysis, following Braun and Clarke's (2006) framework for thematic analysis of qualitative data. Thematic analysis was selected as its flexibility enabled the researcher to inductively interrogate the data to identify themes, ensuring that the resulting findings offered a holistic

perspective concerning the participants' experiences of the study. The findings discussed in this paper focus upon three of the themes emerging from the data: the role of gardening in encouraging expressions of identity; demonstrations of agency; and the development of community.

## **Findings**

### ***Gardening and identity***

During the study, it emerged that participating in gardening activities offered participants the opportunity to express elements of their identity that had become less prominent as they continued on their dementia journeys.

Arthur, a lifelong gardener whose opportunities to garden at home had become increasingly restricted, particularly enjoyed the opportunity to put his gardening abilities into practice once more, and benefitted from the opportunity to work autonomously in the garden. Furthermore, the centre's care staff believed that the ability to participate in an activity that he enjoyed had improved Arthur's level of engagement:

*"When Arthur comes to the centre sometimes, he's great one-to-one, but he tends to fall asleep a lot, and just sort of drift off, but I felt he was really eager to get outside, like really really keen to get outside. And I think with Arthur, because he's type 1 diabetic as well as having dementia, so now for him physically, his family over-worry about him when he's outside in his garden, in case he can't get back up, in case he wanders and stuff, so I think that what you were saying earlier about them having that choice, and speaking to them, and you know, I think that must have been great for Arthur."*

- Interview with Rebecca

*"Arthur's very much more one-to-one... But you've got to bring the best out of him. It's all there, just to come out... you give him the plants and everything, and the hesitation goes away."*

- Interview with Maggie

Similarly, for Claire, who spent her working life in education, and is a mother of ten and grandmother of nineteen, helping and caring for others was an inherent part of her nature. Participating in the gardening sessions enabled her to express this aspect of her character:

*“I wonder if that’s to do with her [Claire’s] job? Because she was an SVQ invigilator, and her husband was a teacher as well, and they’ve got ten children, and 19 grandchildren. So I wonder if that’s that natural sort of wanting to lead as well? You know, sort of walking about, assessing people, and supervising, I wonder if that’s linked to her job?”*

- Interview with Rebecca

Sheila benefitted from the opportunity to share her extensive gardening knowledge:

*“Sheila wasn’t participating, so I asked whether she was ok, and offered to move one of the containers closer to her so that she didn’t have to stand up, because she uses a stick. She said that she was happy just “supervising”, making a joke of it, saying “I’m in charge over here”. She seemed in good enough spirits, but she wasn’t actively participating in the activities like she usually does, and she did seem slightly disengaged. But with her saying that she’s “supervising”, and based on my past observations regarding her eagerness to help the other participants, I think that one of the things that she gets from this project is the opportunity to use her knowledge, and to be the expert.”*

- Researcher observations, week five

### ***Gardening and agency***

From the first session, the participants were invited to select the activities undertaken each week. Claire shared that the collaborative design of the sessions had given her a sense of control and involvement in the project:



*“Claire: It gives you more freedom over what you’re doing.”*

- Post-session interview, week six

Rebecca particularly felt that the freedom of choice afforded to the participants through the project represented an opportunity that was lacking in their everyday lives:

*“I don’t think that most of them have that freedom to just do whatever they want. They’re so restricted in here, there’s so many rules, although you don’t try and enforce them as much, but you know, they can’t go outside wandering because there’s so many risks. Whereas I think this gave them a chance to sort of do what they liked, in a safe environment but not feeling restricted.”*

- Interview with Rebecca

The opportunity to work autonomously in the garden appeared to be particularly enjoyable for Arthur:

*“After we’d planted the spring onions, Arthur went over to one of the other beds of his own accord and started working the soil. I left him to it for as long as possible because I could see that he was really enjoying doing it, and it was interesting to see him engaging independently with the garden like that. To me, it shows that he feels comfortable in the space, and that he was really enjoying the gardening work because he wanted to do more of it. He’s a very knowledgeable gardener, and he identified a task, and took it upon himself to complete it.”*

- Researcher observations, week two

Megan considered the ability to work autonomously and make free choices to be a primary benefit of gardening for people with dementia:

*“I think that’s when it comes back down to that flexibility, and giving people choice and control over things. People want to have that experience, and they maybe don’t- in other situations in life, when they’re being told either they’re not able to do that, you want the garden to not be that environment, where it’s all kind of we don’t do this, and we don’t do that, and I don’t want to see anybody doing that.”*

- Interview with Megan

Victoria indicated that she felt that the group’s successes had defied the expectations of others:

*“Victoria: They didn’t think we’d do it.”*

*“Victoria: You didn’t think we’d do it, did you?”*

*Sarah: I knew you’d do it!*

*Victoria: Surprised you, didn’t it?*

*Claire: [to Sarah] Did you think we would all do it?*

*Sarah: I knew you’d all do it!*

- Post-session interview, week six

Jennifer remarked upon the ability of the garden to offer people with dementia a sense of freedom from the restrictions impinging upon their everyday lives, observing that:

*“They get a sense of glee of defying expectations.”*

- Interview with Jennifer

Perhaps the most poignant illustration of the impact of the project upon the participants' sense of agency was expressed by Claire. At the end of the final interview recording, Claire's voice can be heard, reflecting that:

*"We organised a whole project!"*

- Post-session interview, week six

### ***Gardening and community***

Although improvements in opportunities for social interaction are commonly considered to be a benefit of community gardening initiatives, the recruitment of the participants from a pre-existing social group had led the researcher to question whether this theme would be prominent within the study's findings. However, though the group members were familiar with one another due to their attendance at the day centre, the gardening project offered them an opportunity to create a new social dynamic.

*"Victoria: We all enjoyed it, anyway. It's relaxing, and it gets you away from that crowd in there. [laughs]*

*Sarah: That's another thing I was thinking about, actually. Because obviously you all know each other*

*Victoria: Yes, we do*

*Sarah: But do you feel like this has sort of made you into a different little group, away from the main group?*

*Victoria: Aye, it has. Just try talking to them lot in there!*

*Arthur: We're the gardeners*

*Claire: It's made us into a different unit, hasn't it?*

*Sheila: Aye, it has"*

- Post-session group interview, week six

The emergence of a new social group was also observed by the centre's staff, who expressed surprise in the changing dynamics as a consequence of the study. The staff observed that taking part in the study had given the participants the confidence to break out of their social routine:

*"I could see them moving away from the group that they were used to sitting in, they were letting other people in, they were building up new friendships, stuff they weren't doing in the hall because they were, as I say, some of them would just get into a wee rut, and just be, "I know so-and-so next to me, I'll sit here, I'm safe here". But there's a big room of people, you know, that you would enjoy their company."*

- Interview with Joanne

The group's shared interest in gardening enabled them to create a new group dynamic, distinct from the larger day centre group:

*"Victoria: They're [the other day centre attendees] not interested- it's like talking to a brick wall in there sometimes. They've got gardens, and don't go into them!"*

*Sarah: Oh right, that's a shame!*

*Victoria: If they were keen and that, they could be out here right now!*

*Claire: Aye, if they were keen*

*Victoria: But they don't care enough to do it.*

*Sarah: Yeah. So it's brought you all closer together through a shared interest, then?*

*Victoria: Yes*

*Sheila: Yes"*

- Post-session group interview, week six

The centre's staff also acknowledged the role of a mutual interest in encouraging the development of new friendships:

*“So the fact that they’ve been out, and they’ve built up new friendships over an interest that they all enjoyed doing, that was good.”*

- Interview with Joanne

## **Discussion**

The findings highlight that participating in gardening activities offered the group a forum for expressing and re-connecting with elements of their embodied selfhood and agency, opportunities that were not as available to them in other areas of their everyday lives. Furthermore, the gardening project empowered participants to generate social capital through working together in the garden, facilitating the establishment of a new community.

The garden enabled participants to express their sense of identity and selfhood in a variety of ways. Arthur's independent undertaking of gardening tasks demonstrated the ability of the garden to facilitate expressions of embodied selfhood, with Arthur communicating his desire for independence and his enduring gardening skills through his autonomous engagement with the garden, supporting Kontos' (2011) conceptualisation of embodied selfhood as demonstrated through behaviour reminiscent of a previous vocation. The role of the garden in reawakening such non-verbal expressions of selfhood extended beyond participants with gardening experience; for Claire, who had spent her life as an educator, the freedom to shadow the researcher whilst delivering sessions, and to oversee her fellow participants during activities, contributed to her positive experiences of the project by enabling her to express elements of her identity that had become muted as her dementia journey continued. The centre's staff considered these expressions of identity to be one of the primary benefits of the study.

The role of the garden in encouraging a sense of agency was highlighted by the participants, care staff, and researcher as a fundamental element of the project's success. The study demonstrated that people with dementia are indeed able to express agency, and furthermore,

that empowering people with dementia to demonstrate their agency using creative approaches is crucial to the delivery of meaningful activities for those living with the condition.

In expressing agency through their participation in the project, the participants demonstrated resistance to the structures oppressing them as individuals with dementia. Victoria's repeated declaration that "I bet they didn't think we'd do it!" indicates that the garden enabled the participants to flourish beyond the perceived stereotypes placed upon them due to their condition, defying the stigma and stereotypes informing their lived experience of dementia. The participants' determination to prove themselves through the project highlights the potential of the garden as a forum for the practice of citizenship. Bartlett & O'Connor (2007, p.112) define their concept of citizenship as practice as "*something individuals achieve for themselves, through the power dynamics of everyday talk and practice*", and argue that viewing dementia through a citizenship lens highlights the political meaning of the everyday activities of people with dementia, facilitates the recognition of the behaviours observed in the study's participants as acts of resistance and expressions of power, and contributes to an enhanced understanding of the variety of ways in which people with dementia express agency (Bartlett & O'Connor, 2007). The notion of the garden as a space for freedom and equality, removed from the restrictions of prescribed social structures, has been previously explored in relation to other marginalised groups, but never in relation to dementia, and the findings of this study suggest that the ability of the garden to propagate a sense of liberation and freedom of expression may be particularly pertinent to the value of gardening in dementia care.

The situation of the study within an existing community of people with dementia revealed a surprising finding concerning the social dynamics within such groups. Though social groups such as community centres are commonly considered a means of alleviating the social isolation experienced by people with dementia (Kane and Cook, 2013), the findings suggest that these feelings of isolation endure within social groups designed for people with dementia, and may be exacerbated by spending time with people with whom an individual feels no common ground beyond a shared diagnosis. The garden offered an environment in which the group were able to work together to achieve shared goals, bond over mutual interests, and relate to one another as individuals beyond their shared diagnoses, highlighting the potential of the garden as a platform for the practice of relational citizenship, uniting the twin roles of the garden as a facilitator of the expression of embodiment and citizenship (Kontos et al, 2017).

The findings demonstrate that gardening contributed to increased levels of social capital among the participants. Social capital, defined by Putnam (2000, p.19) as “*connections among individuals – social networks and the norms of reciprocity and trustworthiness that arise from them*” is increasingly recognised as a key component in the promotion of well-being for older people (Nygqvist et al, 2013), but has yet to be explored in relation to dementia. This study indicates that social capital is an essential element in promoting well-being for people with dementia, and suggests that further research into the relationship between social capital and dementia is necessary. Although the generation of social capital is not a benefit unique to community gardens, such environments have been highlighted for their ability to create social capital (Kingsley & Townsend, 2006, Firth et al, 2011), with Glover (2004, p.143) stating that they “*are less about gardening than they are about community*”. For people living with dementia, who often express feelings of loneliness, the notable ability of the garden to empower participants to generate social capital may be fundamental to promoting a more positive lived experience of the condition.

### **Limitations and recommendations for future research**

The design of the study carried some limitations. The researcher initially intended to conduct the study using three discrete groups of participants over three community garden sites, for a twelve-week period. However, due to recruitment challenges and the seasonal nature of the study, the size and duration of the study were ultimately restricted. Though small-scale studies are championed within the methodological paradigms informing this study, a larger-scale intervention may have contributed to a further enhanced understanding of the value of gardening for people with dementia. Discussions with prospective participants revealed that although many were keen to participate, transport to the sites proved an insurmountable barrier. Consequently, the study was conducted in the grounds of a day centre for people with dementia, negating the need for transport. Future studies of this nature may benefit from further exploration of other potential barriers to participation.

The frequency and duration of the gardening sessions were largely driven by pragmatic considerations. Though similar studies conducted in care home settings consisted of multiple weekly sessions, this was deemed impracticable in the context of this study, due to the participants’ limited attendance at the day centre. However, future studies may consider examining the impact of more frequent, or longer, gardening sessions upon the participants’

experiences, should the setting of the research permit. Similarly, research conducted over a prolonged period may further enhance the quality of future studies of this nature, offering a deeper insight into the experience of gardening for people with dementia.

## **Conclusion**

These findings suggest that for people with dementia, gardening is more than an enjoyable leisure activity; it is a forum for the development of identity and selfhood, practice of citizenship, and expression of agency. Through engagement in meaningful activity and re-connection to the natural environment, the participants were empowered to express themselves as capable citizens, articulating their sense of selfhood and agency in a variety of creative methods that were not previously available to them. Furthermore, the project enabled the participants to forge new social networks, developing a social unit based upon a shared interest, rather than a shared diagnosis. By obtaining first-person perspectives from participants and adopting a phenomenological approach to data collection and analysis, the study demonstrated not merely that community gardening is a beneficial activity for people living with the condition, but offered an insight into why community gardening carries such meaning and potential for people living with dementia.

By demonstrating that gardening carries significant meaning and value for those affected by the condition, it is hoped that this study will inspire further research concerning this topic, and contribute to the widespread development of gardening initiatives for community-dwelling people with dementia.



## References

- Alzheimer Europe (2013). *Prevalence of dementia in Europe*. Retrieved from: <http://www.alzheimer-europe.org/Research/European-Collaboration-on-Dementia/Prevalence-of-dementia/Prevalence-of-dementia-in-Europe>
- Bartlett, R., O'Connor, D. (2007). From personhood to citizenship: Broadening the lens for dementia practice and research. *Journal of Aging Studies*, 21(2007), p. 107-118.
- Boyle, G. (2014). Recognising the agency of people with dementia. *Disability & Society*, 29(7), 1130-44.
- Braun, V., Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101.
- Caddell, L.S., Clare, L. (2010). The impact of dementia on self and identity: a systematic review. *Clinical Psychology Review*, 30(1), 113-26.
- Clatworthy, J., Hinds, J., Camic, P.M. (2013), Gardening as a mental health intervention: a review, *Mental Health Review Journal*, 18(4), p. 214-25
- D'Andrea, S.J., Batavia, M., Sasson, N. (2007). Effect of horticultural therapy on preventing the decline of mental abilities of patients with Alzheimer's type dementia. *Journal of Therapeutic Horticulture*, 18(2007-2008), 8-17.
- Davis, H.J. (2004). Dementia: Sociological and philosophical constructions. *Social Science & Medicine*, 58(2), 369-78.

Dewing, J. (2007). Participatory research: A method for process consent with persons who have dementia. *Dementia*, 6(1), 11-25.

European Parliament (2011). *European Parliament resolution of 19 January 2011 on a European initiative on Alzheimer's disease*. Retrieved from:  
<http://www.europarl.europa.eu/sides/getDoc.do?type=TA&language=EN&reference=P7-TA-2011-0016>

Firth, C., Maye, D., Pearson, D. (2011). Developing “community” in community gardens. *Local Environment: The International Journal of Justice and Sustainability*, 16(6), p. 555-568.

Genoe, M.R. (2010). Leisure as resistance within the context of dementia. *Leisure Studies*, 29(10), 303-320.

Gilliard, J., Marshall, M. (2012). Introduction. In J. Gilliard and M. Marshall (Eds.), *Transforming the Quality of Life for People with Dementia through Contact with the Natural World: Fresh Air on My Face*. London: Jessica Kingsley

Glasgow, R.E. (2013). What does it mean to be pragmatic? Pragmatic methods, measures, and models to facilitate research translation. *Health Education & Behaviour*, 40(3), 257-265.

Glover, T.D. (2004). Social Capital in the Lived Experiences of Community Gardeners. *Leisure Sciences*, 26(2), p. 143-162.

Hewitt, P., Watts, C., Hussey, J., Power, K., Williams, T. (2013). Does a structured gardening programme improve well-being in young-onset dementia? A preliminary study. *British Journal of Occupational Therapy*, 76(8), 355-361.

Jarrott, S.E., Gigliotti, C.M. (2010). Comparing responses to horticultural-based and traditional activities in dementia care programs. *American Journal of Alzheimer's Disease & Other Dementias*, 25(8), 657-665.

Kane, M., Cook, L. (2013). Dementia 2013: The hidden voice of loneliness. Retrieved from [http://www.alzheimers.org.uk/site/scripts/download\\_info.php?fileID=1677](http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1677)

Kingsley, J.Y., Townsend, M. (2006). 'Dig In' to Social Capital: Community Gardens as Mechanisms for Growing Urban Social Connectedness. *Urban Policy & Research*, 24(4), p. 525-37.

Knapp, M., Prince, M. et al. (2007). Dementia UK: A report to the Alzheimer's Society on the prevalence and economic cost of dementia in the UK produced by King's College London and London School of Economics. Retrieved from [http://www.alzheimers.org.uk/site/scripts/document\\_pdf.php?documentID=342](http://www.alzheimers.org.uk/site/scripts/document_pdf.php?documentID=342)

Kontos, P. (2004). Ethnographic reflections on selfhood, embodiment and Alzheimer's disease. *Ageing & Society*, 24(6), 829–849.

Kontos, P.C. (2011). Rethinking sociability in long-term care: An embodied dimension of selfhood. *Dementia*, 11(3), 329-46.

Kontos, P., Miller, K-L., Kontos, A.P. (2017). Relational citizenship: supporting embodied selfhood and relationality in dementia care. *Sociology of Health & Illness*, 39(2), 182-98.

Lakey, L., Chandaria, K., Quince, C., Kane, M., Saunders, T. (2012). Dementia 2012: A National Challenge. Retrieved from  
[http://www.alzheimers.org.uk/site/scripts/download\\_info.php?downloadID=821](http://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=821)

Lewin, K. (1946). Action research and minority problems. *Journal of Social Issues*, 2(4), p. 34-46

Mapes, N., Milton, S., Nicholls, V., Williamson, T. (2016). Is it nice outside? Consulting people living with dementia and carers about engaging with the natural environment. Natural England Commissioned Reports, number 211. Retrieved from:  
<http://publications.naturalengland.org.uk/publication/5910641209507840>

McKay, G. (2011). *Radical Gardening: Politics, Idealism & Rebellion in the Garden*. London: Frances Lincoln

Martyn, P., Brymer, E. (2016), The relationship between nature relatedness and anxiety, *Journal of Health Psychology*, 21(7), p. 1436-45

Noone, S., Innes, A., Kelly, F., Mayers, A. (2015). “The nourishing soil of the soul”: The role of horticultural therapy in promoting well-being in community-dwelling people with

dementia. *Dementia*, epub ahead of print. Retrieved from:  
<http://journals.sagepub.com/doi/abs/10.1177/1471301215623889>

Nyqvist, F., Forsman, A.K., Giuntoli, G., Cattan, M. (2013). Social capital as a resource for mental well-being in older people: A systematic review. *Aging & Mental Health*, 17(4), p.394-410.

Putnam, R. (2000). *Bowling Alone: The Collapse and Revival of American Community*. New York: Simon & Schuster

Swaffer, K. (2014). Dementia: Stigma, Language, and dementia-friendly. *Dementia*, 13(6), 709-716.

Van Manen, M. (2016). *Researching Lived Experience, Second Edition: Human Science for an Action Sensitive Pedagogy*. Abingdon: Routledge

Wearing, B. (1998). *Leisure and Feminist Theory*, London: SAGE

White, M.M. (2011). Sisters of the Soil: Urban gardening as resistance in Detroit. *Race/Ethnicity: Multidisciplinary Global Contexts*, 5(1), 13-28

Wolsko, C., Lindberg, K. (2013), Experiencing connection with nature: The matrix of psychological well-being, mindfulness, and outdoor recreation, *Ecopsychology*, 5(2), p. 80-91